

Principles and theory guiding development and delivery of patient education in disorders of thrombosis and hemostasis: Reviewing the current literature

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Abstract

Prior work regarding patient education has identified the importance of using learning theory and educational models to develop and deliver content that will improve patient outcomes. Current literature appears to examine implementation of teaching strategies without clear identification of educational principles. This review aimed to identify educational principles and theory currently utilized in the planning and delivery of patient education in disorders of thrombosis and hemostasis. The majority of articles reviewed evaluated the impact of educational interventions on patient outcomes; links between educational principles and changes in outcomes was lacking. Few articles clearly referenced theory in development of patient education; fewer focussed on the population of interest. The lack of literature demonstrates the need for multi-center collaborative research aimed at generation of an improved level of evidence regarding the most effective theoretical framework for the development, delivery and evaluation of patient education for patients with disorders of thrombosis and hemostasis. Once a theoretical framework for patient education is developed and tested, the unique contribution of patient education to both knowledge and clinical outcomes can be robustly evaluated.

KEYWORDS

education, hemostasis, patient education, patients, thrombosis

Essentials

- Appropriate, theory-based education has been linked to improved patient and system outcomes.
- Literature regarding theory-based education in thrombosis and hemostasis is extremely limited.
- Current literature describes teaching strategy in single centers vs. impact of underlying theory.
- Collaborative efforts are required to make recommendations regarding optimization of education.

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1 | BACKGROUND

Patient education in disorders of thrombosis and hemostasis is an important component in the ability of patients to self-manage these conditions. Appropriate education has been linked to improved patient outcomes in a variety of chronic diseases, as well as in the use of oral anticoagulation.¹⁻⁸ Common outcomes of interest include adherence, health goals, hospital admission rates, and side effect occurrence.⁹⁻¹¹ Effective patient education has been shown to improve patient adherence to prescribed medication (dose and frequency), attendance at follow-up appointments, and utilization of adjunct measures such as compression stockings or diet modifications.^{1,2,9,11-15} Appropriate education has also been shown to decrease hospital admission/readmission rates, as well as decrease the incidence of undesirable medication side effects and interactions.^{2,10-12,15-17} Increased achievement of mutually agreed upon health-care goals has been identified as an outcome of individualized education.^{1,7,8,18}

Prior work in the area of patient education has identified the importance of utilizing recognized principles to develop and deliver patient education.^{4,6,10} Key theories in adult learning are summarized in Table 1 and include those of Friere and Knowles, both of which place the learner at the center of education development and delivery.¹⁹⁻²¹ The participatory approach of both theories recognizes the importance of learners who are engaged in the educational effort as key to producing the desired outcomes.²² Building on these, the Health-Belief Model considers the motivations and barriers influencing an individual's decisions regarding their health-care choices and behavior^{1,15,23} and recognizes the influence these have on engagement and learning. Particularly evident in literature describing pediatrics, developmental theories such as Piaget's provide the basis for general educational interventions and teaching strategy²⁴ and their use-in conjunction with teaching strategy-is well described. In comparison, current health care literature focusses on the use of teaching strategy and description of content without specifically identifying associated theory.^{2,3,9,13,14,16,18,25-41}

1.1 | Educational theory and principles

Educational theory is defined as the "theory of the purpose, application and interpretation of education and learning."⁴² It is comprised of a number of different approaches, each with roots in psychological theory. Educational theory provides for a specific guidance as to which educational interventions to implement and how to assess them.⁴³ A key component of a good educational theory is the ability to implement the theory in a practical setting with the aim of determining utility in "real life." In contrast, principles of education are defined as general guiding truths which may not identify specific interventions or approaches.⁴⁴ The literature discussing education acknowledges that principles and theory are linked, with definitions going so far as to define one with the other.⁴⁴ Regardless of definition or use, implementation of principles and theory into clinical education has been demonstrated to produce improved outcomes in terms of knowledge retention (as demonstrated in medical education)²⁴ as well as therapeutic outcomes.^{15,45}

The aim of this review was to identify the educational theory and principles currently being used in the literature to plan and deliver patient education in disorders of thrombosis and hemostasis. When discussed in the literature, evaluation of the education and/or educational intervention was also noted by the authors. Recommendations are made with respect to future directions for research in this area.

2 | METHODS

A search of PubMed, CINAHL, and Medline databases was conducted using the MESH terms "patient education" and "hemostasis OR thrombosis." The searches were limited to articles published in the English language between January 1, 2007 and April 4, 2017, inclusive.

Articles were sought that described patient education-including delivery, development, and/or evaluation-in either thrombosis or hemostasis. Articles describing the use of specific educational principles or theory in the delivery and/or development of patient education were also included. Exclusion criteria included articles describing patient self-testing, those providing lists of available educational resources, and articles solely providing content for educational material.

The initial search identified 55 citations. Three were found to be duplicate citations and were excluded. The authors were unable to retrieve an abstract or full manuscript for one article and it too was excluded. The full articles were obtained for the remaining 51 citations and reviewed for applicability by 4 reviewers. After the second review, two articles were excluded as they focused on the specific content to be delivered to patients and/or health-care providers, one article described patient self-testing and one listed available educational resources. Thirteen articles were otherwise deemed not applicable to the aim of this review (one discussed prevention of thrombosis in chronic kidney disease, one addressed components of care for patients with thrombosis, and the remainder identified the need for appropriate patient education as a conclusion).

After exclusions, a total of 34 articles remained. Three reviewers extracted information regarding educational principles used, the specificity to disorders of thrombosis and hemostasis, limitations of the article and the population for whom the education was targeted. After this further review, 16 were found to be specific to the disorders of interest. (Figure 1)

3 | RESULTS

Of the 34 articles describing patient education, 7 were literature reviews.^{3,16,30,35,46-48} Our search identified one Cochrane review, which was included.³¹ Twenty-eight articles discussed specific teaching strategies, interventions and/or content^{2,3,9,13,14,16,18,25-41,49-52} without clear identification of any guiding educational or developmental theory. The evaluation of the chosen teaching strategy with respect to patient outcomes was discussed in 10 of these articles.^{9,13,14,17,26,28-30,32,38} Five studies identified increased or

TABLE 1 Educational theories and models

Theories/Model	Key Points	References	Application in practice
Health-Belief model	Developed by social psychologists to explain lack of participation in preventative health care; behaviour depends on individual's perception of four areas: (1) severity of potential illness, (2) susceptibility to the illness, (3) benefits of taking preventative action, (4) the barriers to taking the action; relationship between beliefs and behaviours; ignores social, economic, emotional factors ^{1,2}	[1,46]	Creation of educational strategy for immigrant patients regarding availability and necessity of factor prophylaxis in hemophilia
Gardiner multimodal learning	Educational principle that arises from neuroscience research; learning can be increased through use of more than one sense (visual, auditory, written, combination of all); allows learner to use approach that works best for them ³	[12]	Providing written, pictorial, video information regarding signs and symptoms of a DVT
Fleming's VAK (visual, auditory, kinesthetic) learning styles	Educational principle arising from experience of teachers and students; allows learner to use approach that works best for them ⁴	[19]	Providing written, pictorial, video information—along with hands on practice—regarding self-infusion in hemophilia
Erickson's developmental Stages/Piaget developmental theory	Erickson: psychosocial growth and development theory; aid in analysing/explaining behaviour; individual must successfully progress through each stage in order to successfully complete current developmentally appropriate tasks ⁵ Piaget: psychosocial/cognitive development in childhood; important for understanding how children know ⁶	[12,19]	Providing age appropriate education for children (ie, a picture book aimed at toddlers with hemophilia vs a YouTube video made by other teenagers)
Knowles' adult learning theory	Educational programs for adults must reflect how adults learn and their psychology; adults are self-directed and take responsibility for learning; problem must be immediately important and learners must be informed why they must solve the problem ⁷	[19,47]	A brief, pointed information pamphlet for patients started on chronic anticoagulation highlighting the reason for the medication and where to get more information
Friere's theory	Educational theory that focuses on acknowledgement the people bring own knowledge and experience to their learning; learning occurs through interaction and in a variety of ways ⁸	[19]	Education regarding activity based prophylaxis in hemophilia vs. standardized dosing (ie, 2x/week)
Nursing theories: Peplau, King, Orlando	Peplau: focus is on therapeutic relationship between nurse and client; interventions and evaluation based on mutual behaviors/outcomes ⁹ King: focus is development of a relationship that allows achievement of mutually agreeable goals; goal attainment is affected by stress, time, roles ¹⁰ Orlando: focus is nursing process; patient treated as individual that has constant input into own care; guides evaluation of care in objective patient outcomes ¹⁰	[48]	Deciding on choice of factor replacement product (regular vs. extended half-life product) Deciding on choice of anticoagulant for chronic atrial fibrillation or DVT

DVT, deep vein thrombosis.

improved adherence to medication and treatment recommendations after specific interventions regarding delivery of information to patients.^{13,14,29,32,38} Five studies identified increased patient knowledge^{9,14,26,28,34} while one intervention⁹ demonstrated improved practical skills. Only one study noted a lack of improvement in patient outcomes after an educational intervention.³⁰

Nine articles discussed conditions other than disorders of thrombosis and hemostasis^{13,14,19,33–38} while 5 articles identified approaches to generalized patient education.^{18,39,47,48,50} Eight articles discussed the education of health-care providers with respect to the provision of patient education.^{2,13,19,25,26,36,37,40}

Six articles^{1,12,19,46–48} referenced educational principles/models, developmental and nursing theory in their descriptions of patient education (Table 1). Three articles not only clearly referenced underlying educational theory and principles, but also identified specific teaching

strategy or intervention and the utilization of evidence-based content.^{1,12,19} Evaluation of the intervention was noted, however in all three it was conducted with respect to content and/or utility of the strategy/intervention.

Sixteen articles discussing education for patients with disorders of thrombosis or hemostasis^{1,2,8,9,12,16,25–32,46,49} were included in this review (Table 2), with the majority (13/16) focussed on disorders of thrombosis. Twelve articles concerned single-center experiences,^{1,2,8,9,12,25–29,32,49} while the remainder were literature reviews. Two of the 16 described specific educational interventions in the form of studies,^{9,27} however in both articles, educational principles were identified in the context of teaching strategies, making it difficult to identify the unique contribution from each. Only three provided a description of education planning and delivery that was completely consistent with our aim.^{1,12,46}

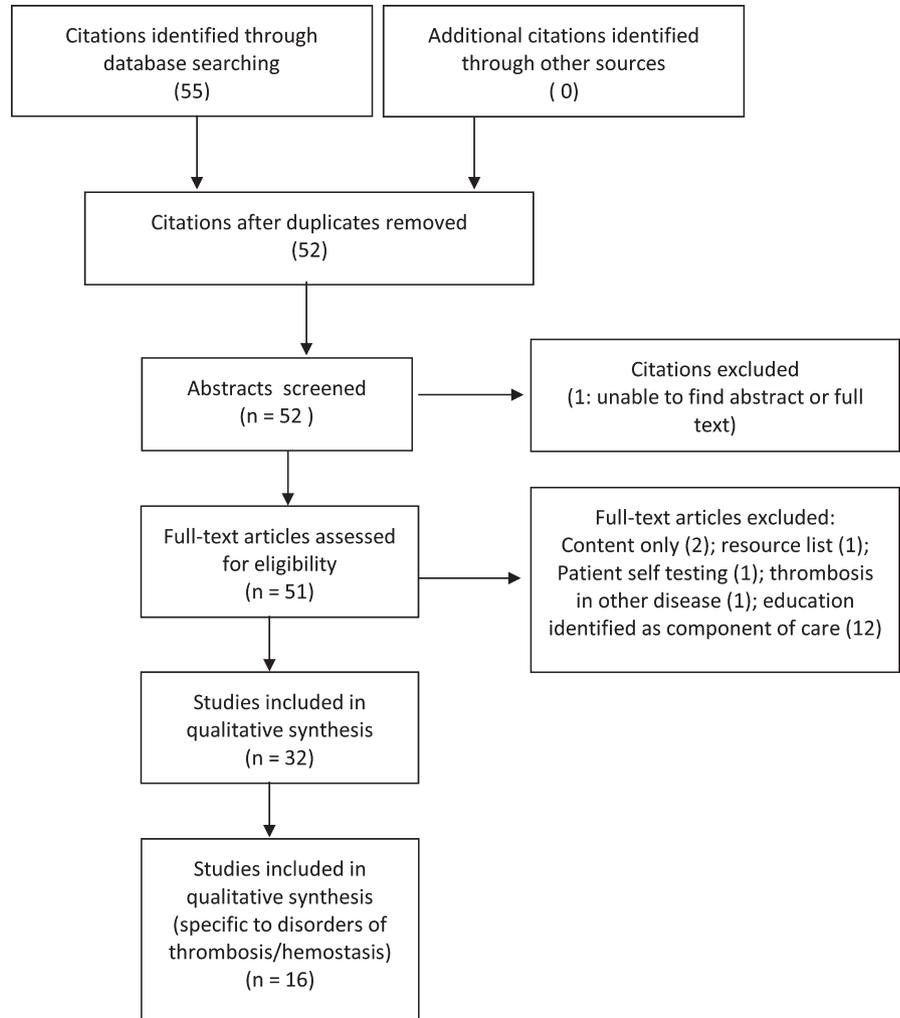


FIGURE 1 Literature search procedure

4 | DISCUSSION

Patient education has long been recognized as an important contributor to successful self-management of a variety of chronic diseases, as well as improved patient outcomes.^{6,9,11,46,51} Recent literature in disorders of thrombosis and hemostasis focuses on describing and evaluating teaching strategies and content rather than exploring the impact of the underlying educational principle or theory.^{1,2,16} While it does make sense to ensure that patients possess the correct knowledge, the manner in which to best develop and deliver this information remains unclear.

4.1 | Thrombosis

Content standardization facilitates communication of key learning goals, thereby increasing the likelihood of improved outcomes. The majority of publications describing education in disorders of thrombosis identified what to teach, as opposed to how to teach it. Most articles emphasized content related to self-management of anticoagulation (when to take medication, when to do blood work needed, diet modifications) and symptom recognition (how to identify a deep vein

thrombosis²⁵). Only a few discussed education regarding home testing of the international normalized ratio (INR) or prothrombin time,¹⁶ or the reason for requiring the medication. Variability in topics such as conducting home testing are likely reflective of differences in health-care systems and care approaches while lack of discussion of others (ie, rationale for medication) may be due to underreporting and single-center focus of the majority of the papers. Variability is also likely a function of the population of interest—education aimed at patients is likely to be more comprehensive in scope, while education aimed at the health-care providers conducting the education is likely to be narrower due to assumptions concerning the knowledge and practice of the provider. Examination and evaluation of content was beyond the aim of this review—however, the gaps and variability in content lend strength to the thought that standardization of content would likely improve outcomes in this patient population.⁴⁹

This review reflects the growing body of literature in this field describing teaching strategy and its evaluation in terms of impact on patient outcomes. Given that education for patients requiring anticoagulation often occurs in hospital and over a short period of time,³² this strategy fits well with the adult learning theory concept of providing education around an immediately important problem, and lends itself

TABLE 2 Summary of education literature specific to disorders of thrombosis and hemostasis

References	Aim	Population/Disease	Method	Conclusion/Outcomes	Limits
Crumley ¹	Evaluation of patient response to an educational handout based on the Health Belief model	Patients Thrombosis (post-thrombotic syndrome prevention)	Patients with DVT in 1 center filled out a patient education survey after reading education developed based on Health Belief model	Education based on Health Belief Model resulted in self-reported intent to comply with treatment recommendations	Single center Small sample size (N=13)
Shaha et al. ²	Development and implementation of evidence based patient and family education	Patient and Health Care Providers Thrombosis (general oral anticoagulation)	Community-based, participatory design including interviews, documentation review, nurse-survey	The inclusion of the multidisciplinary team and patients resulted in the development of an education program that was implemented in 1 center	Single center No sample size noted No program/education evaluation No discussion of specific principles/theories
Rose ⁸	Highlight importance of education for patients on oral anticoagulation	Patient Thrombosis (oral anticoagulation for atrial fibrillation)	Opinion and summary of another article	More attention is needed to patient education. Education must be ongoing and involve patients	Acknowledges that there is a gap in the literature regarding how best to educate patients
Mulders et al. ⁹	Determine effect of improved education on patient outcomes	Adolescent and Adult Patients Hemostasis (hemophilia)	Hemophilia patients randomized to receive e-learning program or no program Questionnaire and observation of infusion pre-learning and post-learning	E-learning group demonstrated higher knowledge of hemophilia and improved practical skills improved education results in improved outcomes	Small sample size (N=30 total; 15/group) No information provided on the educational program
Baumann ¹²	Describe the development of educational materials for pediatric patients with thrombophilia based on theories by Erikson, Piaget, Gardner	Pediatric Patient Thrombosis	Literature search to determine features that facilitate learning Development of educational materials based on these findings Evaluation of materials by experts in field	Education is a component in adherence Education should be appropriate to age/stage of development	Description of development only finished product not evaluated through use of material
Woffard et al. ¹⁶	Systematic review of best practices to inform patient education with warfarin administration	Patient Thrombosis (warfarin use)	206 articles initially found, 166 excluded Data extracted re setting, study design, sample size, content source, educational strategy/domains, evaluation of knowledge	Education should be evidence based There is a paucity of evaluable data	Small sample sizes in the applicable literature (N=average 3 to 5) Limited studies available using validated tools to evaluate education
Cranwell-Bruce ²⁵	Identification of material that should be taught to patients Review of one teaching strategy (repetition)	Health Care Providers Thrombosis (general oral anticoagulation)	Opinion-based article, some review of the literature to inform content	Information taught should be consistent between providers	Opinion article No identification of theories/principles
Lee et al. ²⁶	Evaluation of web-based, interactive education vs passive-didactic slides	Health Care Providers Thrombosis (VTE prevention)	Health care providers randomized into 2 groups, changes in knowledge evaluated after each intervention	Web-based education was marginally effective, passive-didactic slides were more effective Consider motivation for learning	Small sample size Web-based education included passive slides as well

(Continues)

TABLE 2 (continued)

References	Aim	Population/Disease	Method	Conclusion/Outcomes	Limits
Furmedge et al. ²⁷	Identification of educational needs of parents learning to infuse factor	Parents of patients Hemostasis (hemophilia)	Focus groups with parents of children with hemophilia Data analyzed thematically	Need for support was more important than information Education must incorporate the needs of the learner	Small sample size No identification of theories/principles of education
Reger et al. ²⁸	Evaluation of a pharmacist managed anticoagulation program in a single center	Patient and Pharmacist Thrombosis (injectable anticoagulation; VTE prevention)	Observational study Data collected re: patient adherence to treatment, VTE recurrence, medication inventory	Most patients (180/207) completed the educational program The most time is spent on education	Single center No identification of theories/principles of education
Fairbairn-Smith et al. ²⁹	Investigation of the effect of an educational book on patient knowledge and TTR	Patient Thrombosis (general oral anticoagulation)	Consecutive patients were enrolled completed a questionnaire pre and post reading the educational book	The book increased time in therapeutic range providing written education and assessment can improve outcomes	Small sample size (N=24)
Wong et al. ³⁰	Review of evidence re supplemental patient education for patients on OATs and effect on clinical outcomes	Patient Thrombosis (general oral anticoagulation)	Systematic review Searched Medline, EMBASE, CINAHL, Cochrane Central Register of Controlled Trials, International Pharmaceutical Association Methodology was assessed using GRADE	1326 records initially identified, 7 included in systemic review, 5 included in meta-analysis supplemental education as way to improve outcomes is not supported by literature but quality of studies is poor	Small number of studies included (N=5) All studies included had 1 or more methodologic limitation
Clarkesmith et al. ³¹	Evaluation of the effect of education and behavioral interventions on TTR	Patient thrombosis (oral anticoagulation; atrial fibrillation)	Cochrane Review. Literature included was identified from EMBASE, CINAHL, MEDLINE, PIYEHjfffo	Self-monitoring plus education was not favored Insufficient evidence exists to make conclusions about impact of education on TTR	Small study size (N=8)
Piazza et al. ³²	Determination of whether education will increase adherence	Patient thrombosis (Venous thromboembolism prevention)	Patients scheduled to receive injectable VTE prophylaxis Adherence measured by doses administered vs doses scheduled	Individualized education was associated with higher adherence Refusal rates lower after education	Single center
Schrijvers et al. ⁴⁶	Review of determinants of adherence	Patient hemostasis (hemophilia)	STROBE method to appraise articles From 880 initially found, 44 were assessed and 5 matched domain, determinant, and outcome	There is a lack of literature Need patient-initiated information vs questionnaires (based on Health Belief Model)	Small sample size (N=5). The 5 studies included had non-representative samples
Michaels et al. ⁴⁹	Review of advantages/disadvantages of teaching patients to do INR self-testing, information needed, patient selection, teaching strategies	Patient thrombosis (general oral anticoagulation)	Opinion-based review of literature to inform content	Effective, appropriate education and consistent content results in improved patient outcomes-- specifically safety	Opinion article No identification of theories/principles

INR, international normalized ratio; TTR, time in therapeutic range.

Bold indicates educational principle/theory.

TABLE 3 Common educational themes in the thrombosis and hemostasis literature

Theme	Sub theme	References
Engagement	Education should be adaptable to reflect patient motivation and achieve mutual goals the patient should be involved in their own education (through both development and delivery)	Crumley, Shaha et al., Rose, Baumann et al., Lee et al., Furmedge et al., Fairbairn-Smith et al., and Schrijvers et al. ^{1,2,8,12,26,27,29,46}
Accessibility	Both content and method of delivery need to be appropriate to patient population (age, disease, end goal, literacy, language, etc.)	Crumley, Shaha et al., Mulders et al., Baumann et al., Lee et al., Furmedge et al., Schrijvers et al. and Michaels et al. ^{1,2,9,12,26,27,46,49}
Evaluation	Both content and delivery method need to be evaluated using measurable/observable outcomes	Crumley, Shaha et al., Rose, Mulders et al., Baumann et al., Vickers, Lee et al., Fairbairn-Smith et al., Clarkesmith et al. and Piazza et al. ^{1,2,8,9,12,16,26,29,31,32}
Standardization	Basic and/or important content should be the same no matter the delivery method This content should be evidence based	Rose, Baumann et al., Vickers, Reger et al., Wong et al., Clarkesmith et al., Schrijvers et al. and Michaels et al. ^{8,12,16,28,30,31,46,49}

to immediate evaluation of effectiveness. It does therefore, provide a more practical and accessible approach to theory-based patient education. The issue, however, is that strategy often arises from theory,⁴⁴ and the lack of distinction between the two made it difficult for us to determine which had the biggest effect on the outcome of interest.

Our review returned two articles discussing theory-based educational strategies in disorders of thrombosis,^{1,12} neither of which made a clear case for–or against–their use. In one, the Health Belief model was used to develop a patient information book for adults, and in the other, a variety of developmental theories were used to design patient handouts for children. Given the specificity of developmental theory, this approach to education development could be perceived to be quite restrictive in its use compared to the generalizability of the Health Belief model; the lack of evaluation and the different patient populations meant we were unable to draw definitive conclusions as to the effectiveness of one theory over the other. As the majority of patients on anticoagulation are adults, the difference in patient ages also made it difficult to draw conclusions as to the effect of theory-based education on patient outcomes in general in this disorder.

4.2 | Hemostasis

In contrast to the breadth of literature reporting education interventions for patients with thrombotic disorders, there is a paucity of literature discussing education in disorders of hemostasis. It is not possible to identify from the published literature why this disparity in focus on education may exist between these two populations. Patients with disorders of hemostasis are often managed by the same clinical teams that manage patient with thrombosis, so this discrepancy is unlikely due to fundamental differences between treating clinicians. We propose the lack of focus in the literature on educational theory in disorders of hemostasis may reflect the chronic nature of such disorders. Patients requiring anticoagulant therapy usually do so after an acute event. In contrast, patients with disorders of hemostasis are commonly diagnosed shortly after birth and live with the disorder for the duration of their lives. Education may thus become a lifelong journey rather being seen as an episodic process requiring strategy and theory.

Further investigation of this issue is likely needed to ensure optimal educational approaches are utilized for this population.

The literature discussing education in disorders of hemostasis focussed on achievement of key learning goals through a variety of teaching strategies, aimed at a diverse target population. Reflective of the inherited nature of these disorders, education targets included adolescent and adult patients, as well as parents and caregivers. Most articles focussed on the development of practical skills (self-infusion, infusion of child), with one discussing improvement in patient knowledge in relation to its effect on treatment adherence. This variability is likely due to the forced separation of two related care priorities–in order to successfully administer recommended treatment, key learning goals (initiation of an intravenous catheter^{9,27}) must be met. Conversely, when examining adherence rates, patient and caregiver knowledge must be considered.⁴⁶

As in disorders of thrombosis, there was a focus on increasing patient knowledge–especially with respect to practical, clinical information. The focus on skills and adherence in education of this patient group, however, continues to illustrate the difficulty that exists in the literature in separating teaching strategy from the educational principles underlying it. Table 2 identifies the conclusions reaches in this literature–while themes such as patient engagement and patient needs informing education are part of several theories of education (Table 1), these are not identified as contributing to the development of the education explored–rather, they are identified as future needs.

4.3 | Limitations

The limitations of our review should be noted. Educational principles used to guide patient education in relation to other chronic diseases have been published, but were not within the aim of this review. Given the increasing prevalence of thrombotic disease coupled with the significant advances in treatment modalities used across the subspecialty of hemostasis, the authors felt a targeted review was warranted. The publication date limits were selected in order to keep this review closely reflective of contemporary patient education practice–therefore it is likely that articles relevant to our aim were not included. Most of the studies described in the literature have small sample sizes

(N=1 to N=24) and fail to utilize validated measures for evaluation - this likely contributes to a lack of clarity regarding the relative contribution of strategy and theory-based education within the published literature.

4.4 | Future directions

Despite the variability reflected in the findings, the common themes identified in Table 3 demonstrate an informal set of guidelines regarding the development and delivery of patient education. This review supports not only the common understanding that increased patient engagement is likely to result in improved patient outcomes,^{1,46} but also the concept that patient engagement in their own education includes the understanding that education should adapt and reflect individual motivation for learning while allowing for the achievement of mutual health care goals. This type of patient involvement not only increases engagement, but works to ensure accessibility of information. Both the content and the delivery method need to be appropriate to the target population in order to successfully accomplish the goal. The articles in this review which focus on teaching strategies and interventions highlight the significance of increasing accessibility of education through consideration of patient age, literacy, language, disorder and learning environment.^{26,28,49}

Future research should be founded upon the lack of formal consensus regarding which principles should guide development and delivery of patient education. Efforts should be made to conduct studies designed to appropriately compare the impact of theory-based patient education to current practice on well-defined, objective patient and system outcomes. This, in combination with validated outcome measures, will aid in addressing the lack of reliable evaluation of educational interventions/approaches and will allow for ongoing evaluation.

The lack of literature consistent with our aim reflects the challenges of conducting multicenter trials related to the issue of patient education. As a result, there is a paucity of widely validated resources to support optimal delivery of patient education. Notwithstanding this however, is an emerging pattern of understanding that education delivered to patients that is informed by education and learning theories is likely to yield improved outcomes in terms of knowledge attainment and retention. General Information regarding educational, learning and developmental theory is found in education/psychology journals—although an internet search for “educational theories” results in resources such as handouts from the University College of Dublin (<https://www.ucd.ie/education>) and websites such as Learning Theories (www.learning-theories.com). Discussion of these in the context of health care can be found in certain medical and nursing journals.^{19,24,53,54}

5 | CONCLUSION

Despite acknowledgement that validated educational theory and principles should guide patient education, this review demonstrates that the available literature continues to focus on discussing specific

teaching strategies and appropriateness of content as opposed to examining the educational principles used to guide its design and delivery. Given the available literature, it is difficult to make compelling recommendations regarding how to optimize the process of educating patients and families regarding their thrombosis or hemostatic disease. From the available evidence presented here, the Health Belief Model appears to result in the most appropriate written educational material for pediatric patients and their caregivers, while adult education theory appears to be the most appropriate—albeit obvious—choice for education developed specifically for adult patients. However, neither of these have been validated within multi-center trials. Future collaborative research requires a focus on the determination of appropriate, effective educational principles that will result in improved patient outcomes. This is important given the attention paid to patient education internationally. Only through multi-center collaborative research will robust recommendations regarding the optimal approach to patient education be determined; and only then will the true contribution of good quality patient education to clinical outcomes be able to be determined.

AUTHOR CONTRIBUTIONS

J. Hews-Girard reviewed articles and wrote the manuscript. C. Guelcher and J. Meldau performed the initial literature search and reviewed the manuscript. E. McDonald reviewed the manuscript. F. Newall provided direction for the literature search and reviewed the manuscript.

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